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An ethical exploration of the narratives surrounding substance use and pain management at the end of life: a discussion paper

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Abstract

This discussion article examines narrative positioning related to pain management for people who use substances at the end of life. We explore how dominant narrative genres associated with biomedicine, such as ‘restitution’ and narratives common within the context of drug services such as ‘recovery’ can hinder effective pain management within this population. We argue that these discourses can marginalise the ethical self-identity of patients who use substances at the end of life. It can also trouble health and social care professionals in supporting patients and generating counter-narratives that challenge those often associated with substance use. Stigma is a common experience for this population with stereotyping as ‘junkies’ and associated with criminality. They are positioned as drug-seeking, and this requires more surveillance at the end of life when opioid therapy is potentially more available and authorised. This can make it challenging to generate ‘companion’ stories that are positive and maintain moral adequacy. Dominant biomedical narrative genres often prevent the recognition of the fractured stories that people using substances can often present with. This can lead to narrative silencing and to the under treatment of pain. The person’s self-identity is invested in narratives of recovery, and opioid use symbolises their addicted past because for practitioners, this population is at clinical risk with the potential for drug seeking behaviours. Whilst not requiring formal ethical review this discussion paper was constructed in accordance with good scientific practice with the work of other researchers respected and cited appropriately.

Keywords

Substance Use, End of Life, pain management, Palliative care, narratives, ethics

Introduction

This article seeks to explore the context of pain management at the end of life for people who use substances. These reflections are based on a wider unique project funded by (National Lottery Community Fund) examining end-of-life care for people who use substances.¹ This theoretical exploration stems from

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data generated from five strands of the project which included a rapid evidence assessment (REA),² interviews with individuals with palliative care needs who use substances.³ Interviews were also conducted to explore family, carer and friends' experiences of people using substances at the end of life,⁴ to examine practitioners' perspectives⁵ and to gain key informant insights into the issues pertinent to this population.⁶ We examine the dominant narrative genres that frame the stories related to pain management and substance use and how this delineates and defines the ethical landscape. We argue that the narrative positioning of 'recovery' remains unhelpful within the context of end-of-life care with implications both for health and social care professionals and people who use substances. We contextualise these data through a narrative approach^{7–11} highlighting how constructions such as 'recovery' narratives can unhelpfully define the frames of reference for appropriate responses to people using substances at the end of life.

We all generate our narrative lives through different elements or fragments of the available cultural repertoire.¹¹ Stories therefore become either good or bad companions and as adapted, collected and (re)interpreted they become material semiotic companions. Stories are never unique but are collected, more like 'reassembled fragments on loan'¹¹ that retain the genesis of standard character, plot and style in a recognised schema. Within biomedical narratives, the dominant or canonical biomedical genres,¹⁰ grand narratives or master narratives¹² do not convey single unified stories but often present as ensembles of repeated themes. These themes can become oppressive, particularly in this case, focusing on recovery or restitution within a population that is nearing the end of life. If a patient is unable to present a coherent, recognisable narrative (e.g. through lack of social capital or because of stigmatising attributes), then they are more open to narrative silencing.¹¹ How well a person is able to present a counter-narrative,¹² for example, not to be cast as a 'junkie', can be challenging, particularly being able to present new less oppressive 'companion' stories which support rather than stigmatise them.

Background

In the last two decades, there has been an increase in older drug users and a subsequent rise in rates of death from non-drug-related conditions.¹³ This increase means that current and previous substance users now survive long enough to die of conditions more commonly found in deprived cohorts of the wider population.¹⁴ Furthermore, changes in life expectancy in the general population are leading to a pattern of population ageing which is likely to be mirrored in the smaller population of substance users. This means predictive end-of-life care is needed since this population is not just dying due to acute overdose but rather other chronic conditions such as cancer, heart or respiratory disease.

Pain management within the context of people using substances can be challenging, and within acute clinical settings, it can be suboptimal or non-existent.^{15,16} Stigma is likely to exacerbate the problems for this population, particularly if using Goffman's¹⁷ definition as an 'an attribute that is deeply discrediting'. For example, popular media representation of people using substances as 'junkies' based on prolific heroin use and criminality.¹⁸ Patients are drug seeking rather than having 'legitimate' reasons for opioid-based pain medication. Specifically, stigma theory developed by Earnshaw and Chaudoir¹⁹ suggests that structural and social stigma, associated with substance use, is experienced by individuals as enacted, anticipated, and internalised.¹ For a number of people using heroin, the treatment regime itself became stigmatising and set people up to expect more stigma from other parts of the health and social care system.¹⁸ Radcliffe and Stevens¹⁸ referred to segregation in pharmacies and the supervised consumption of medication as a humiliation and thus monitoring at the end of life reinforces their 'Junkie' status. This stigma associated with substance use can lead to diagnostic overshadowing²⁰ where health professionals, in this case, attribute behaviours to substance dependency rather than to the pain associated with end-of-life conditions. This can lead to poor pain management at the end of life for people with problematic substance use.²¹ We interpret stigma as affecting different levels of social life, and Pescosolido et al.'s²² framework is helpful in focusing

on the micro or psychological level factors, the meso or social network level factors and macro or societal wide factors. Examining all these aspects also moves the narrative away from the individualisation of health and examines wider health (in)equality. For example, Imtiaz et al.²³ notes that in the United States crude mortality rates of drug- and alcohol-induced causes of death have increased but is disproportionately borne in lower socio-economic strata and throughout high-income countries there are extreme health inequalities across a range of health conditions.²⁴

Pain management is one of the pivotal priorities in effective palliative care. There is a general consensus within the evidence base that the most pressing problem in relation to substance misuse is not the phenomenon itself. Rather, it is the continual under treatment of pain in this population at the end of life, driven by the unexplored concerns related to opioids misuse.^{25–30} Levels of prescribing may need to be higher for people using substances because of their tolerance to opioids from historic drug use. This may contravene established clinical guidelines in terms of opioid titration.

Farnham²⁸ describes how uncertain prescribers may withhold medication and appropriate doses. There is also a fear of overdose and drug diversion of prescribed medications within this population group.^{30,31} Templeton et al.,⁶ for example, found there was a clear acknowledgement by health professionals of this issue in the approach to pain management quoting,

We talk about the pain . . . what the patient tells you it is but that doesn't seem to apply to this group in terms of other people, 'so they're looking for drugs, they've asked for it four hourly', whereas if it was a wee old lady who was 80 who was asking for extra painkiller, they'd be paging us going, 'She's really sore, you need to come and do something about it.

Some literature recognises that psychiatric co-morbidities can lead to 'chemical coping' strategies. This is defined in this literature as the potential for patients with a history of substance use to access illicit drugs in an attempt to control unmanaged pain. Authors also mentioned 'pseudo-addiction'; behaviours that are misunderstood by health and social care staff as drug seeking (when patients 'act out' when distressed), rather than originating from poor or inadequate pain control.²⁵ There has been a challenge in using the label of 'pseudo-addiction' on both grounds of limited evidence and a logical inconsistency since people with a history of substance use cannot have a pseudo-addiction as it is part of their history and therefore this label is not applicable.³² Some papers³⁰ also delineated a need to distinguish between tolerance, physical dependence, and addiction, although they did not specify how this can be achieved.

Narrative positioning and substance use

Differing narrative approaches can be adopted and taken up by both patients and practitioners. How they position themselves to these companion stories has important implications and impacts on approaches to pain management for practitioners and people using substances at the end of life. Narrative approaches provide a lens to examine narrative positioning and draw out the dominant discourses that may impact care practices in this population. We argue that more dominant narrative genres can minimise and marginalise the experiences of patients, making it more challenging for practitioners to respond effectively to the complexity of people using substances at the end of life. It can also affect the self-identity of the patient in managing the consequences of stigma. Evidence suggests that these populations are narratively silenced and more stigmatised than other groups.^{33,34} Frank³⁵ refers to the predominant narrative within medicine as linked to restitution in that medical interventions are designed to restore the patient back to their previous good health. When patients present with a more chronic and fractured, 'chaos' narrative then this becomes more challenging for them and practitioners to recognise a coherent story and makes them more likely to

misread the stories generated. This chaos narrative can often characterise the presentation of those patients using substances.

Often within biomedical genres, narratives precede and authorise medical interventions, with the official story subsuming subsequent developments as either successful or failed technical procedures. Being a good practitioner means being able to construct narratives that persuade others of an ordered reality requiring identifiable effective actions.³⁶ Hence, someone using substances at the end of life may present with multiple confounding variables that could affect standard protocols for pain management. They present with a 'chaos' narrative³⁵ that is perceived to need quantifying and medical assessment in order to assess risk. Frank³⁷ highlights a protocol-driven system that fails to examine the cultural frame in which it is heard. If the answer to a question does not fit with the practitioners expectations then patients could face difficulty getting the care needed. These 'canonical biomedical genres'¹⁰ carry moral imperatives. It is an ethical requirement to identify, assess and address aberrant drug seeking behaviour. If the person using substances at the end of life takes up this narrative construction it becomes an ethical imperative to abstain from illicit drug use and avoid opioid use, even at the end of life, since it is perceived to be associated with ethical inadequacy and a moral failure to strive for a narrative of recovery. The internalisation of these narratives can inflict a kind of systemic oppression on their self-identities, and it derives from taking up unhelpful narrative genres that can be damaging to identity construction.

Mattingly¹⁰ asserts that healing narratives associated with biomedicine provide 'an authorized action framework'¹⁰ in order to interpret both the narrative ground and expectations of how these healing dramas should unfold. In the enactment of this narrative structure, other 'facts' or voices that do not coherently fulfil the narrative construct are silenced. This may be exacerbated by culturally endorsed stereotypes of substance users being associated with criminality and other stigmatised health conditions such as HIV disease, mental illness or hepatitis C.³⁸ There is also evidence to suggest that people using substances are likely to be perceived as having personal control over these problems and subsequently more liable to be blamed and held responsible for the consequences of these actions.^{39,40} This is reflected in health professional attitudes with Boekel et al.⁴¹ suggesting they perceive substance users to be violent, manipulative, and poorly motivated, leading to a task-orientated approach to care delivery with limited empathetic engagement by staff. Galvani et al.⁵ also found a clear acknowledgement of this issue by health professionals in approaching pain management, the assumption being that patients with a history of using substances often exhibit drug-seeking behaviours. These dominant or 'master' narratives¹² are often archetypal, constituting recognisable plots, schemas and stories, for example, the manipulative drug user who will fake symptoms to get opioids. Such oppressive master narratives also cause doxastic damage in distorting self-image and self-identity of the person using substances.³⁸ They also involve a recognisable repertoire of character types that do not form single unified stories but often present as ensembles of repeated themes. In terms of methodological approach, we examined data that related to pain management from the REA.² This was a major theme generated from the REA through textual narrative synthesis.⁴² From the remaining strands of the wider project, we identified data specifically addressing issues of pain management and examined these data, as a team, in light of the findings of the REA. We examined narrative context to all these data and used positioning theory⁴³ since this can provide a framework in which performance is enacted with the positioning of the self in personal narratives generating self-identity.

Narratives of surveillance and clinical uncertainty

There are clear concerns for practitioners regarding pain management at the end of life for people using substances. Galvani et al.⁵ give examples from practice of people who had misused prescribed pain medication, including one person who had buried illicit drugs in the grounds of the hospice for use when he went into the gardens; others who sought prescriptions for opiate-based medication from multiple

sources including the oncologist, general practitioner (GP), and hospital; the misuse of pain patches including smoking them, dissolving them and sharing them out, and selling on some of their pain medications. Use and misuse of pain medication by family members or friends was also highlighted as a problem. These examples highlight the 'borderlands'⁴⁴ of clinical encounters when potential marginalisation can take place. Populations that may not present a coherent, recognisable, culturally appropriate narrative frame, but rather have a more 'chaotic', fractured narrative can be open to cultural misrecognition and stigma.¹⁰ This requires health care professionals to engage in what Mattingly¹⁰ describes as 'narrative mind reading' in which they need to explore and acknowledge the complexity of a person's narrative life and avoid stereotyping people using substances, for example, as just someone exhibiting drug seeking behaviour. If health professionals position people as 'flat' characters whose self-narrative becomes an insignificant subtext to the plot of diagnosis, treatment and recovery, then a person-centred approach to pain management is difficult to implement and maintain.

Within the literature, pain management is the topic most common to emerge in relation to substance use at the end of life.² Within this literature, there appeared conflicting narratives between narratives of abstinence and risk reduction within substance use at the end of life, with surveillance often offered as a strategy to monitor safe opioid use. This surveillance was based on a recommendation for universal screening for substance misuse, urine testing, and sometimes pill counting.^{25,27,31,45,46} There was an emphasis on the need to use validated tools.^{27,31,47} Some papers recommended or used a particular measure to assess potential opioid misuse.^{21,26} There is insufficient evidence, however, to confidently support the accuracy or efficacy of most of these instruments.⁴⁷ The feasibility, acceptability and clinical impact of these instruments remain uncertain, with instruments potentially too lengthy to realistically administer in most clinical settings. There is limited generalisability with a lack of evidence relating to evaluation of the impact of these instruments.^{46,48,49} Within most biomedical narratives, this surveillance is an ethical requirement often predicated on risk assessment. The practitioner has to demonstrate professional propriety and moral accountability even if the evidence suggests these current strategies are ineffectual. This is similar to other strategies such as urine drug testing, considered a 'gold standard' in terms of substance misuse identification.^{46,49} Although it may be helpful in risk identification, there is a lack of evidence to support its accuracy or effectiveness in predicting, preventing or reducing substance use behaviours in chronic pain patients.^{49,50} There is a high potential for false negatives or false positives that may compromise diagnostic accuracy and patient-health professional relationships. Patients could perceive an implicit message within this interaction that health professionals are not interested in what they say but will only trust test results. There are also issues of cost-effectiveness and accessibility as well as difficulty interpreting the results.

The desire to maintain moral adequacy with ineffectual surveillance strategies is not often problematized by practitioners. Surveillance becomes part of narrative silencing by narrowing the focus of interest to a set of guidelines to manage pain rather than an opportunity to engage with the narrative complexity often affecting this population at the end of life. This is not to suggest that there are no genuine concerns of safety and vulnerability, such as the potential for opioid diversion—whether relating to either the patient selling, or their family/friend using or selling, prescribed opiates. There are limited, evidence based solutions like limited supply of medication, written opioid agreements or prescription monitoring programmes.^{27,28,30,31,51} For example, opioid treatment agreements may, in practice, be discriminatory and actually intensify stigma. They may also be implemented inequitably.^{52,53} Rather than seeking protocols that stereotype people using substances and lack robust evidence and evaluation applying a more person-centred approach would seem a more appropriate approach. Narratives that stigmatise people using substances can have significant consequences in end-of-life care. For example, there is evidence that hospice staff have concerns about insufficient access to anticipatory end-of-life medications and under-prescribing for this group of patients from GPs who are concerned about drug misuse as Galvani et al.⁵ comment,

I think sometimes I've had an issue where GPs . . . have been reluctant to put end of life anticipatory medications in if they know there's been a history or there's some people in the family that have got problems with drug use . . . I think, generally speaking, there's a huge ignorance in managing pain in patients who are either current drug users or past drug users at end of life with cancer. There is a fear isn't there about prescribing?

Talking about substance use

There are a number of issues of concern in relation to pain management, substance use and communication. From a narrative approach, people make sense and interpret their lives through stories, justifying and positioning themselves. It constitutes and grounds identity formation and therefore exploring the underlying concerns through a narrative approach can potentially identify some of the wider cultural context in which these positions are (re)framed. Underpinning most of the current literature on pain management and end-of-life care was the prerequisite to effectively and often directly communicate with this population.^{27,28,51} Whether this happened, how to achieve it and what sort of strategies would be helpful in managing direct conversations about substance misuse was not a feature of the current literature. Talk, Taylor⁵⁴ reminds us, is the site and range of practices in which our identities are constituted out of the cultural narrative resources available. 'Thus identities are in part conferred through positioning and in part actively constituted, contested and negotiated by active speakers' (p. 99).⁵⁴ If health professionals need to distinguish between active users, individuals in methadone replacement therapy, and those in recovery,³⁰ then narrative complexity requires narrative intelligence. An awareness of the companion stories that may help or hinder a person in constructing their self-identity. These require comprehensive, open and non-judgemental negotiations that many general health professionals may feel ill equipped to undertake. This is particularly challenging when many health professionals interpret risk in terms of their personal safety and feel incompetent in approaching this population.⁵⁵ This issue is highlighted by Galvani et al.⁵ who quotes a hospice health professional:

I know that I struggled with thinking about the drugs and what to suggest prescribing. I mean if somebody's on so much Diazepam that they're taking, you know, what do you then do in terms of symptom management? How do you manage their anxiety when they're already taking shed loads of Diazepam?

For people using substances and their families, the world of clinical encounters can generate unfamiliar languages, rituals and expectations about how to act their part. Moreover, as Radcliffe and Stevens¹⁸ accounts of enacted stigmatisation in treatment and accessing prescriptions reveals, people using substances and their families may well be anticipating similarly stigmatising attitudes from all health practitioners and so adopt quite defensive positions. People using substances may present a fractured narrative unfamiliar to clinicians or as Mattingly¹⁰ comments; worse still, they may appear as 'familiar strangers', prejudged and slotted in categories where they are dismissed, invisible, neither known nor deemed worth knowing.

Some patients appear to be concerned that their level of substance use will preclude them from having pain and symptom management at high enough levels.^{5,6} Their competence and ability to present a narrative frame that maintains moral adequacy is often compromised. In this sense, maintaining moral adequacy and accounting for the ethical self is a critical element within any narrative.⁸ This aspect is further articulated, not just in assumptions about drug-seeking behaviour but in that some people will resist or refuse some medications (e.g. opioids) because of their history of substance use.⁶ They have worked hard on maintaining a narrative of recovery, of restitution, and these medications represent a failure in this process. Effective communication in examining and working with these narratives to support patients with substance use problems at the end of life is an important element of a person-centred approach.

Communication about the goals of care and substance use is also significant with some patients not being able to, or wanting to, stop using for a range of reasons, including unresolved underlying issues such as experiences of abuse or trauma. This complexity cannot be reduced by biomedical narrative canons to a

problem focused ‘puzzle’ for the practitioner to solve using their clinical expertise¹⁰ with minimal input from the person themselves. Life experiences of people using substances have generated storied resources that both enable and constrain a speakers’ identity work. Working with people to explore the meanings attached to the narratives presented can support patients who require a clear realistic assessment of the narrative context of care. Patients, for example, exposed to narratives that stigmatise people using substances may stockpile medications or not give an accurate baseline of illicit drug use for fear of under-treatment.⁶

Pain management, social networks and narrative diversity

People live in networks rather than isolated from the social context of life and these form integral parts of people’s narratives. This is often not acknowledged within formalised healthcare,⁵⁶ and there is a need to recognise the impact and importance of families and peers, and whether they can positively support the person using substances at the end of life.^{4,6} This is particularly important since the context related to family and peers may, in this population, be detrimental to good pain management (with potential risk of people stealing or diverting medicines) or be positive—given the dearth and inaccessibility of effective social care for disenfranchised populations. The context of managing end-of-life care for people using substances is an important issue and the identification of significant others in the person’s life can facilitate safe and meaningful care at the end of life. Templeton et al.⁶ gives an example of how one narrative included a pub landlady looking after the medication for one isolated pub regular. She was his designated next of kin, kept the anticipatory end-of-life medications and looked out for his safety – noting if he did not come into the pub. For those who were homeless, it was sometimes a shelter worker or a friend at a hostel who was closest to the person and could potentially assist with medication, but this required proactive engagement from health and social care staff to facilitate this.⁵⁷ Radden and Fordge⁵⁶ challenge the ideology of individualism prevalent with biomedical narratives that can isolate and define the subject in a way that compounds social isolation:

Consistency suggests that what was begun by others should be continued by them. And this point would not so readily be lost from sight were the distorting ideology of individualism which casts each person the master of their fate and captain of their soul to be replaced with more realistic, collectivist assumptions—as it surely should be.

Within pain management at the end of life, one of the primary health professional goals is to assess, titrate and monitor a patient in terms of safe doses of opioid and adjuvant medications for symptom control. Substance use can make this goal challenging without fully engaging with the complex fractured narratives that some patients can present with. These narratives often include a set of ‘characters’ who are not often recognised and acknowledged by health professionals, as in the examples above. The plot becomes that of a ‘troublesome familiar stranger’,⁹ a ‘drug abuser’ presented as acting in predictable but unreasonable, unaccountable and possibly immoral ways. It therefore becomes ethically legitimate to monitor family, and to assess support workers and peers for signs of medication misuse. Without being open to narrative diversity, the stories and characters that have significance for the patient are minimised.

Caught between conflicting narratives

A challenge to the management of pain and symptoms can be the differing views and approach of professionals between abstinence and risk reduction, from narratives that stigmatise people using substances and those that are more inclusive and supporting. The existence of stigma would suggest some encounters with health professionals could be more judgemental and task-orientated in approach compared to a more

empathetic approach from others, and this can make it difficult for patients using substances to know what to expect and perhaps anticipate the worse. Narrative constructions can have a direct clinical impact, for example, Galvani et al.⁵ indicate some health and social care professionals were not worried that cancer patients may become dependent on opioids and that there should be no difference when talking to patients using substances about the right titration of medication for them. One area, however, where there appeared to be conflicting opinion between health and social care professionals was related to whether a patient should be asked or told to stop their own substance use in order to receive medication for pain and symptoms, particularly opioid medication.⁶ Some staff felt every vial of morphine should be accounted for while others felt that counting medications was meaningless in the face of imminent death. This can cause difficulties with substance use treatment services who often advocate for abstinence, presenting a narrative of recovery.^{58,59} This can make managing pain at the end of life challenging from both the reluctance of health professionals to prescribe or give appropriate doses of opioids and from patient who is in recovery and does not want to risk psychological and physical burdens associated with addiction. Instances where people with histories of substance use refused opiate-based medication even at the end of their lives are challenging.⁶ As Galvani et al.⁵ quotes one hospice professional:

I've come across the opposite, where people with a drug problem in the past are so reluctant to consider painkillers again because they're so fearful, . . . I do have another lady on my caseload just now, who is an ex user. And interestingly, she really will not take it. She won't take the liquid morphine, she's terrified of taking it. She'll try and put up with the pain, because of that fear of addiction.

However, Templeton et al.⁶ describes family members' experiences of relatives who had a history of drug use but now abstinent, reaching the end of life. The family often insisted that medical staff did not prescribe opioids for as long as possible since the person in recovery did not want the associated problems they experienced with addiction. The utility of recovery when someone is approaching end of life is questionable. The 'recovery' narrative, in this context, silences other stories and reduces the available narratives, for example, a 'good death' based on effective symptom management. As Frank¹¹ would suggest, the companion stories that could be taken up and positioned by people using substances are silenced by, in this case, a grand narrative of recovery. Without this effective counter-story, identities are marginalised and silences are distilled within narrative foreclosure.

Conclusion

Effective pain management for end-of-life care for people using substances can be challenging for a number of reasons. Health professionals often feel that they lack the expertise and confidence to manage pain requiring higher opioid titration that may exceed standard prescribing protocols for end-of-life care. This requires creative thinking and an acknowledgement that pain is more than a physiological response, with this population potentially experiencing significant previous trauma that can affect emotional and psychological distress at the end of life. This requires narrative intelligence that ultimately opens up the storied lives of patients using substances in a way that engages with the meaning(s) that we attach to the disease process that confronts us. This is significant because it can affect how we manage and approach symptoms of pain at the end of life. This needs relationship building and effective communication rather a formulaic, protocol driven pain management process. There is a wider issue with narrative ethics that is important to articulate which centres on narrative privilege: whose narrative is excluded or silenced? Stories can be good or bad companions. Some companion stories can be helpful, so stories of drug recovery, of renewed 'self-recovery' founded on the principles of abstinence can be a significantly supportive narrative in the lives of someone using substances. There also needs to be an acknowledgement that narratives related to abstinence

may actively discourage people using substances from seeking adequate pain relief at the end of life since this may be associated with a 'chaos' that they have worked hard to overcome. For these reasons, narrative intelligence and effective multi-agency working is not only important, it is an ethical imperative to support pain management in this marginalised population at the end of life.


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